



**Manchester
Metropolitan
University**

Hearn, Jasmine Heath, Rohn, Edward J and Monden, Kimberly (2022) Isolated and anxious: a qualitative exploration of the impact of the COVID-19 pandemic on individuals living with spinal cord injury in the UK. *Journal of Spinal Cord Medicine*, 45 (5). pp. 691-699. ISSN 1079-0268

Downloaded from: <https://e-space.mmu.ac.uk/628189/>

Version: Published Version

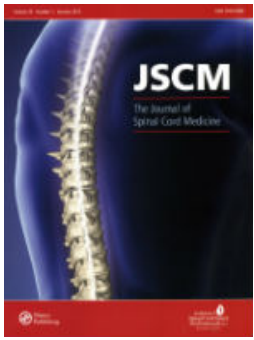
Publisher: Taylor & Francis Ltd

DOI: <https://doi.org/10.1080/10790268.2021.1949562>

Usage rights: Creative Commons: Attribution-Noncommercial-No Derivative Works 4.0

Please cite the published version

<https://e-space.mmu.ac.uk>



Isolated and anxious: A qualitative exploration of the impact of the COVID-19 pandemic on individuals living with spinal cord injury in the UK

Jasmine Heath Hearn, Edward J. Rohn & Kimberley R. Monden

To cite this article: Jasmine Heath Hearn, Edward J. Rohn & Kimberley R. Monden (2021): Isolated and anxious: A qualitative exploration of the impact of the COVID-19 pandemic on individuals living with spinal cord injury in the UK, The Journal of Spinal Cord Medicine, DOI: [10.1080/10790268.2021.1949562](https://doi.org/10.1080/10790268.2021.1949562)

To link to this article: <https://doi.org/10.1080/10790268.2021.1949562>



© 2021 The Author(s). Published with license by Taylor & Francis Group, LLC



Published online: 22 Jul 2021.



Submit your article to this journal [↗](#)



Article views: 183



View related articles [↗](#)



View Crossmark data [↗](#)

Research Article

Isolated and anxious: A qualitative exploration of the impact of the COVID-19 pandemic on individuals living with spinal cord injury in the UK

Jasmine Heath Hearn ¹, Edward J. Rohn ², Kimberley R. Monden ³

¹The Department of Psychology, Manchester Metropolitan University, Manchester, UK, ²The Department of Interdisciplinary Health Sciences, Oakland University, Rochester, Michigan, USA, ³The Department of Rehabilitation Medicine, University of Minnesota Medical School, Minneapolis, Minnesota, USA

Objective: People living with spinal cord injury (SCI) are often immunocompromised, and at increased risk of respiratory infection. Given the restrictions in response to the COVID-19 pandemic, those with SCI may be at increased risk of health deterioration, though how this is experienced is poorly understood. This study explored the experiences of people living with SCI during the COVID-19 pandemic.

Design: Participants completed an online survey consisting of demographic questions, and open-ended qualitative questions pertaining to their experiences during the pandemic. Thematic analysis was utilized for the analytical approach.

Setting: Community-based sample in the UK.

Participants: Participants were recruited via social media outlets of UK-based SCI-specific support charities, and snowball sampling ($N = 42$, $F = 34$, $M = 8$).

Results: Key themes included: (1) lost access to health services and support, capturing concerns surrounding barriers to healthcare and rehabilitation, which intensified secondary consequences of SCI such as spasm and pain; (2) health anxiety, which was perpetuated by perceived heightened vulnerabilities to respiratory complications; (3) social isolation, with significantly reduced social contact, even with care providers, compounding health experiences.

Conclusion: People living with SCI during the COVID-19 pandemic experienced a variety of personal physical, psychological, and social challenges, each of which could disrupt daily functioning and quality of life. Increased utilization of telehealth is recommended to support continued engagement in rehabilitation, and foster connection and community amongst others with SCI and health professionals.

Keywords: SCI, COVID-19, Pandemic, Infection, Isolation, Thematic analysis

Introduction

Current evidence suggests the need for increased self-management support efforts in spinal cord injury (SCI) to reduce secondary complications, in particular in the context of the COVID-19 pandemic, which has worsened psychological distress among individuals with disabilities.¹ However, the rapid rise of COVID-19 cases

(often requiring hospitalization in severe cases) threatens the capacity of health care systems around the world. There is continued concern that many countries will continue to face a critical shortage of life-saving resources, including insufficient numbers of hospital beds, medical staff, personal protective equipment, and ventilators. Access to ventilators may be of particular concern to people with SCI, who often experience respiratory impairment, poorer cough ability, weakness in respiratory muscles, and increased susceptibility to illness.² Indeed, evidence suggests that respiratory complications

Correspondence to: Jasmine Heath Hearn, Department of Psychology, Manchester Metropolitan University, Bonsall Street, Manchester M15 6GX, UK. Email: j.hearn@mmu.ac.uk

This article has been republished with minor changes. These changes do not impact the academic content of the article.

remain the most common cause of mortality following SCI,³ particularly in the first year after injury but people continue to suffer from respiratory complications throughout life.⁴ As evidence continues to be collated, it has been suggested that people with SCI would likely be at increased risk of morbidity and mortality by COVID-19, citing poorer cough ability and weakness in respiratory muscle as potential risk factors.⁵

At the same time, mandatory social distancing policies and ‘stay at home/shielding orders’ were put in place for those who are clinically extremely vulnerable to infection (e.g. people undergoing active chemotherapy, or with severe respiratory conditions such as chronic obstructive pulmonary disease). Shielding refers to government advice for such groups to protect themselves by not leaving their homes and minimizing all face-to-face contact. These measures were intended to protect those particularly at risk of infection from further complications, deterioration in health, and people could also be assessed by their GP, with a decision made as to whether they should be on the ‘shielding’ list. However, such measures may also limit access to essential services for people with disabilities, including access to personal assistants and social care staff. This has been recognized by the World Health Organisation⁶ who also raised concerns that those with need for continued support from personal assistants may be at increased risk of exposure, due to an inability to maintain social distancing. Being on the shielding list, as well as limited access to services, have the potential to worsen secondary complications, particularly for individuals with SCI who are at high risk for respiratory infections, skin pressure injuries, and urinary tract infections. Indeed, in a recent global survey of concerns surrounding COVID-19 and SCI, 60% of practitioners felt that information provided to people with SCI was not enough, and 34.1% of practitioners had been contacted by people with SCI regarding concerns surrounding COVID-19, particularly surrounding vulnerability to infection, inability to obtain testing, and access to transport.⁷ Whilst the above work is helpful in understanding practitioners’ experiences, no work has sought to understand the perspectives of those living with SCI.

The purpose of the present study, therefore, was to explore the impact of the COVID-19 pandemic on individuals living with SCI using a qualitative inquiry approach, including changes to daily life, personal challenges, positive experiences, and potential future impact of the pandemic. We used an open-ended survey that

complements current ongoing quantitative work exploring key mental health and quality of life outcomes in people with SCI. This ongoing work has identified that individuals with SCI have experienced difficulty accessing medical supplies due to the pandemic, with approximately half of participants expressing concern that discrimination through medical rationing was occurring. Likewise, this quantitative work has demonstrated that the COVID-19 pandemic has had a negative impact on the mental health of people with SCI. The present study, therefore, aimed to explore and expand understanding of these issues in further qualitative detail.⁸

Materials and methods

Design

A qualitative, online survey study design was employed, based on recommendations by Braun *et al.*,⁹ who advocate qualitative surveys as a method to allow focus on peoples’ views, experiences, and meaning-making practices, and to obtain richly detailed and nuanced data. This approach has been successfully utilized in a body of previous research within the health context⁹ (e.g. endometriosis¹⁰) and can facilitate affordable and relatively easy access to geographically dispersed populations, which is particularly important in the context of time-limited research related to COVID-19. Likewise, this strategy allows researchers to gain rich (er) insights into the topic of interest. People with SCI were recruited with support from UK community-based SCI charities, who shared the study information across social media outlets after which a snowball sampling approach could be used with those who participated in the study. Upon completion of the survey, participants were also asked to share with their networks where appropriate to support recruitment.

Participants

Eligible participants were those living in the UK currently, and living with SCI for a period of at least one year. Our approach emphasized diversity and inclusivity in order to explore sense-making across people with SCI, rather than within a particular sub-group. Indeed, the use of qualitative surveys means that the sample will be more diverse than in a smaller-scale study. Anybody living with a SCI was invited to participate, and there were no additional exclusion criteria.

Procedure

All authors, all of whom have qualitative and quantitative research experience and/or clinical work in the field

Table 1 Survey questions.

-
1. The world has changed so much in the last few months. Many people are worried about their health, their jobs, their families, and even just day-to-day living. What kinds of changes have you experienced personally? How do you feel about these changes and their impact on you, your family, and your job?
 2. What have been your key personal challenges during the pandemic? How do you feel about these challenges? (e.g. health, safety, access to healthcare, condition self-management, future prospects, family/relationships etc.)
 3. What positive experiences have you had since the pandemic started? How do you feel about these experiences? (e.g. more time with family)
 4. We imagine that having a spinal cord injury may lead to different experiences during this pandemic than for someone without an injury. Can you provide 2 or 3 examples of how your pandemic experiences have or have not been different for you, as compared to friends and family without a spinal cord injury?
 5. If you could change any part of your community's response to the pandemic, in a way that would help you, what would you change and why?
 6. If you could give advice to a friend who also has a spinal cord injury, who may be struggling during the pandemic, what would you tell them?
 7. Thinking about the future, how do you think your experiences during this pandemic will factor into whatever comes next for you?
 8. Is there anything we haven't asked about that will help us understand your experiences during COVID-19?
-

of SCI (two psychologists; one medical anthropologist), designed the survey. The survey was developed on Qualtrics and piloted with colleagues who have a SCI to check for appropriateness in terms of time to complete, clarity of questions, and depth and length of responses produced. Upon publication of the survey online, individuals meeting the inclusion criteria were invited to review the information provided in the participant information sheet by clicking the link to access the survey. If they wished to enroll in the study, participants were then able to indicate their consent in Qualtrics, before proceeding to the survey. The survey was open for participation from 30th September 2020 to 28th October 2020. During this time, there was no national lockdown in place and positive COVID-19 cases were increasing rapidly. On 5th November 2020, one week after the survey closed, the UK entered a four-week national lockdown. Prior to the survey being distributed, the UK had been through one previous national lockdown (23rd March 2020, eased in June 2020), and numerous regional lockdowns to combat local outbreaks (e.g. 4th July regional lockdown in Leicester).

Measures

Demographic and Injury-Related Information. Following consent, participants were then asked to complete 10 questions pertaining to their demographic details, including age, gender, ethnicity, level of injury, cause of injury, year of injury, and injury completeness.

Qualitative Survey. The purpose of this questionnaire was to capture the views of people living with SCI on a number of aspects of their life during the COVID-19 pandemic. The survey utilized open-ended questions in which participants were invited to expand on or discuss their thoughts and experiences, in as much or as little detail as they preferred. This technique has

been advocated by researchers as a practical and effective method of collecting rich qualitative data.⁹ The qualitative survey questions can be found in [Table 1](#).

Data analysis

Data were analyzed using an inductive approach to Thematic Analysis^{11,12} by all authors. Thematic Analysis was used to identify latent themes, which were underpinned from a relativist social constructionist perspective, *i.e.* acknowledging that individuals mentally construct their world of experience through cognitive and social foci and processes.¹³ A social constructionist epistemological stance allowed the researcher to theorize sociocultural contexts and structural conditions which may influence experiences during the COVID-19 pandemic.¹¹ Data were first read a number of times to gain familiarity, whilst initial interpretations were logged and links between participant accounts acknowledged. Next, the responses were coded according to short descriptors that captured the content of each section of a participant's response. Following initial coding, similar codes and relevant extracts which supported each code were grouped according to similarities. Code groups were then refined and reviewed in order to reorganize codes and merge groups according to psychological concepts to finally represent the themes that were commonly represented in the data, as well as providing depth of insight into the experiences participants shared. To ensure rigor, quality, and credibility, all authors were involved in the analysis; KM and ER took part in the process by reviewing the themes developed by the first author. This involved thorough review of themes and their corresponding quotes to ensure the findings were grounded in the data after the initial analysis. All authors discussed thoughts, ideas and interpretations

Table 2 Participant demographics.

	N	%
Gender		
Man	8	19.0
Woman	34	81.0
Ethnicity		
White British	37	88.1
White European	2	4.8
Irish	1	2.4
Chinese	1	2.4
Any other white background	1	2.4
Level of injury		
Cervical	11	26.2
Thoracic	17	40.5
Lumbar or Sacral	4	9.5
N/A (SCD)	7	16.7
Not reported	3	7.1
Cause of injury		
Fall	7	16.7
Road traffic accident	10	23.9
Sporting injury	5	11.9
Non-traumatic	16	38.1
Prefer not to say	4	9.5
Time since injury		
1–5 years	13	31.0
6–10 years	6	14.3
11–15 years	9	21.4
16–20 years	4	9.5
21+ years	10	23.8
Completeness of injury		
Complete	13	31.0
Incomplete	29	69.0

throughout this process in order to identify themes that best captured the data in the most appropriate and representative way.

Statement of ethics

This study was approved by The Research Ethics Committee at Manchester Metropolitan University. All participants provided informed consent and were provided with debrief information following completion of the study, which included a reminder of the purpose of the study, the research team's contact details, and signposting to relevant charitable organizations for participants to reach out to for further support if desired. All applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research.

Results

The final sample consisted of 42 people living with SCI (in line with recommendations for the online survey methodology and analytical process utilised⁷), all of whom were over 18 years of age (no upper age limit) and had either paraplegia or tetraplegia (see Table 2 for further demographic detail). The sample was

largely White British (88.1%) with a mean age of 50 years old (SD = 12.5 years). In contrast to the demographic of the SCI population, the majority of the sample were female ($N = 34$, 81%).

The analytical procedure resulted in the identification of three themes centered on: (1) lost access to health services and support; (2) social isolation; (3) health anxiety. Each theme captured a facet of life during the COVID-19 pandemic, including accessibility, as well as the overwhelming implications of the restrictive measures in place to prevent the spread of the virus. Table 3 presents further quotes representing each theme.

Lost access to health services and support

By far the most common concern (articulated by 32 participants) was the issue of lack of access to health services and SCI-specific support, particularly in relation to rehabilitation:

Lost access to rehab facility, hydrotherapy. Had to have all healthcare appointments cancelled, delayed for months & limited face to face reviews. Still waiting for urodynamics investigations and have still not seen my urologist & rehab team. Home rehab severely curtailed due to shielding so unable to go to supermarket, shops. Still waiting for driving assessment. (Participant #18¹, LoI²: Thoracic)

All therapies (hydrotherapy, physiotherapy, massage) stopped with lockdown, and I could feel the physical gains I had made (very slowly, very painfully) slipping away. (Participant #38, LoI: Lumbar-Sacral)

The above quotes highlight central concerns held by the majority of participants, which centered on the sudden loss of access to health services and often entailed the cancellation of important review consultations for key health functions such as urology. Concerns surrounding physical health were raised, with one participant highlighting the deterioration in their physical strength alongside their increase in pain. In a similar vein, others echoed concerns surrounding a lack of access to services, reflecting on the benefit of face-to-face appointments in terms of enhancing and maintaining their motivation to engage in rehab activities:

[not] having my physio appointments face to face due to Covid-19 restrictions has meant that I haven't been able to continue to recover to the

¹Respondent ID Number

²Level of injury

Table 3 Themes and examples of further corresponding quotes.

Lost access to health services and support	<p>Also many appointments have been canceled such as wheelchair maintenance, MRI scans, bladder checks and EMGs. Cardio departments, however, as well as some female health screening clinics are still going ahead. None of it makes sense as to what continues and what is canceled. With SCI we need many health services, and when they're canceled or significantly delayed the results can be serious. (Participant #21, SCD)</p> <p>I have had several urine & kidney infections over the summer but have not been able to see a health professional. The standard of care I have received has not been of an adequate standard ... I have felt extremely low and depressed at times but unsupported by any health care team. (Participant #18, LoI: Thoracic)</p> <p>I can no longer afford a Carer. I live on my own and I am frightened of doing transfers. The council has given me a red button but I am still scared every time I transfer. (Participant #33, LoI: Thoracic)</p> <p>It has meant I haven't had any check-ups/scans with the spinal unit which I would normally do. (Participant #8, LoI: Cervical)</p>
Health anxiety	<p>I feel less inclined to go out [for a] walk. I visit my elderly mother a few times a week. But then go home and mainly stay in away from people. (Participant #36, LoI: Cervical)</p> <p>I was so scared of catching COVID-19 as a single Mum of 2 children aged 14 & 12. (Participant #43, SCD)</p> <p>Trying not to get sick as I don't want to go into hospital again. I've had sepsis since discharge and been back into hospital 3 times in 6 months. I am anxious about COVID risk. (Participant #29, LoI: Cervical)</p>
Social isolation	<p>Lost all of my social contact in terms of physical meetings- social events, pubs, meals etc. I only have contact with my live-in carers. Luckily I have two long term good carers whom I get on well with which makes a huge difference. (Participant #8, LoI: Cervical)</p> <p>I see very few people now. I haven't seen my children or grandchildren since March. I occasionally see my parents but we socially distance when I do. (Participant #14, LoI: Thoracic)</p> <p>I am really lonely as I cannot get out by myself. Social media, just, saves my sanity. (Participant #33, LoI: Thoracic)</p>

best that I want. Not having face to face motivation. (Participant #28, LoI: Cervical)

The quotes presented underscore the potential negative implications for ongoing rehab engagement and health outcomes because of impeded access to and disengagement from such activities.

For others, the impact of the pandemic on health services meant that accessing important personal protective equipment and other SCI-related equipment such as wheelchairs was impeded, due to resources being pooled into management of urgent cases only:

...not being able to access healthcare due to limited capacity and only 'urgent' cases being seen. Not being able to get latex/nitrile gloves for essential bowel care. (Participant #12, LoI: Lumbar-Sacral)

I need a new wheelchair as the one I have is far too big which impacts my health and pain but I have not heard from my wheelchair services since the lockdown started. (Participant #20, LoI: Cervical)

The lack of access to medical care and personal protective equipment again held implications for specific SCI-related self-management activities such as bowel care and pain management. Both of these are important secondary consequences of SCI that require careful management, and the implications of the lack of access to

provisions described could feed into further complications. This emphasizes the ways in which lack of access to healthcare could hamper engagement in activities of daily living and social participation, key markers of the impact of disability on engagement in everyday life.

Alongside concerns surrounding physical health, and also arising from the prioritization of health service provision being on urgent medical care, the inability to effectively engage in rehab, or attend regular follow up appointments often translated into feelings of anger, sadness, and fear for their health management:

My appointment with a specialist has been cancelled once again, meaning that it is now more than two years since I had follow-up for bowel disease all because of COVID. I feel really sad and am now getting angry, but I'm still fearful. (Participant #9, LoI: Thoracic)

Finally, whilst the large majority of respondents discussed losses in access, some were able to acknowledge improvements in accessibility:

I have found the world to be much more accessible as a result of the pandemic. I have worked from home, attended training and meetings from home, had GP and hospital appointments from home – I am now considering postgraduate

study from home. (Participant #37, LoI: Thoracic-Sacral)

As described above, the increased utilization of online/phone consultations with medical professionals was seen to be beneficial and improved accessibility to healthcare for some participants. This also helped them to widen their prospects and allowed one to begin graduate studies as a result.

Health anxiety

Following the initial focus on the lack of access to health services on physical health, 27 participants turned to the implications of the pandemic on their mental health, with many reflecting on their concerns regarding being at increased risk should they contract the virus:

I am anxious not [*sic*] to get COVID-19 as I fear that I would not fare well. (Participant #9, LoI: Thoracic)

Such concerns surrounding being at risk, meant that participants were anxious to avoid activities that may expose them to the virus, and led many to approach their local health services to discuss shielding in order to protect themselves. In many cases, participants described not getting the outcome of being ‘approved’ to be added to the shielding list, which led to further health anxiety:

I felt I needed to be shielded. GP refused to put me on the list. I was very distressed as my partner with Diabetes had to do the shopping as [we were] unable to get an online shopping slot. I have Asthma caused by SCI and have suffered with 4 episodes of Pneumonia and chest sepsis (hospitalised) in last 3 years. (Participant #32, LoI: Thoracic)

For many, sustaining their SCI had contributed to/led to the development of secondary conditions/consequences such as asthma and pneumonia. This left participants feeling as though their SCI-specific concerns surrounding immunosuppression warranted acknowledgement and additional protection from the virus and activities that could increase their risk of exposure. This health anxiety fed into social behaviors and concerns surrounding other activities of daily life, such as going to work:

I was more worried about going into work due to the risk of infection. I was also more worried about attending hospital appointments. (Participant #25, SCD³)

³Spinal Cord Disease

For others, however, concerns regarding their health and risk should they become infected motivated improved self-care/management to prevent any potential exposure to the virus, as well as to prevent their own health from deteriorating and increasing their risk of exposure to already overwhelmed health services:

I suppose I am taking even more care of my health during this pandemic. Not because I am worried about getting Covid (I am rarely out now) but I was previously prone to UTIs which would escalate quickly, and I’d end up in hospital for a short stay. I’m now making sure I keep as healthy as possible, so I do not need to go near a hospital or even my GP. I feel anxious thinking of having to go to hospital or GP surgery. (Participant #30, LoI: Thoracic)

I am so extra careful with my health as I don’t want to be in hospital for any length of time during this pandemic. So, I would say this is an ongoing challenge. (Participant #30, LoI: Thoracic)

The fear surrounding the risk of catching COVID-19 served as a strong motivator to optimize self-care due to the acknowledgement of being immunosuppressed. This manifested for some in terms of their previous experiences of repeated urinary tract infections, which was cause for concern that they might be put at greater risk of exposure to the virus and an already limited health service should they need to go to hospital for treatment. This was a continuous challenge rather than a one-time obstacle to overcome, which served to maintain anxiety surrounding health management over an extended period of time.

Social isolation

A third major challenge (described by 30 participants) was of the imposed isolation and social distancing guidelines. For many, leaving their homes meant that they were unable utilize their available social support:

I have gone weeks at a time and not left my home. I have not been able to see, meet up with friends and have felt very lonely and isolated. (Participant #20, LoI: Cervical)

I live on my own, so this has been a very lonely period, I haven’t seen my family for 8 months, and I’ve seen very few other people in during the pandemic. (Participant #38, LoI: Lumbar-Sacral)

For many, the isolation described had been ongoing for months, and also extended from friends and family to

feeling isolated from others in their community. The restrictions on travel on an already potentially restricted group, meant that it was even more difficult to utilize important social support in a helpful way. This was often distressing and could lead to a surge in mental health issues. Indeed, the distress caused by the lack of social contact led to attempts to maximize social contact:

I feel totally isolated, forgotten and stressed out, so much so am trying since March to move home back to Lincolnshire where the help I need (private paid at the least) is there for me. (Participant #42, LoI: Cervical)

As above, some participants described the steps they had taken to ensure that they were able to be around others who could accompany them, and lessen the sense of isolation, loss, and stress felt. However, attempts to maximize social contact appeared few and far between, and were described as limited in their success. This, alongside concerns regarding immunity/health status (as outlined earlier), reinforced the isolation and loss of ability to engage in meaningful activity, which often compounded physical health:

I am now isolated. I live in a tiny hamlet and have been advised due to ongoing medical problems to shield. My work, though voluntary, kept me socially and mentally active. Not going out has mental implications, but also, I have added weaknesses because I'm not driving, loading my chair or self-propelling with any speed or distance whilst in the house. (Participant #21, SCD)

Again, as with their concerns surrounding their health and susceptibility to the virus, the isolation experienced as a result of the preventative measures put in place was also a continuous challenge. Whilst some participants mentioned strategies they used to keep their minds occupied, such as voluntary work, all participants described the mental health implications of the isolation.

Discussion

This paper represents the first rigorous understanding of the experiences of people living with SCI in response to the COVID-19 pandemic and subsequent restrictions put in place to manage the outbreak. The results demonstrate the significant, wide-ranging impacts of the virus and infection control measures on people with SCI. These ranged from concerns regarding deterioration in physical health as a result of impeded access to health services, particularly rehabilitation activities such as physiotherapy, as well as potentially

as a result of catching the virus itself, given the increased risk of respiratory complications and immunosuppression experienced by people with SCI. Similarly, concerns regarding the impacts of social isolation on mental and physical wellbeing were discussed, with functional losses described as a result of being unable to use a wheelchair in the more prolonged ways they usually would. Such concerns, particularly surrounding isolation, can induce frustration,¹⁴ low mood,¹⁵ and poorer quality of life,¹⁶ all of which are central outcomes in SCI care and rehabilitation.

While their concerns are not unique, the added vulnerabilities of SCI, such as respiratory vulnerability, immunosuppression, reliance on caregivers, and wheelchair use, can compound public health concerns overall for this population. The results capture the concerns surrounding vulnerability to illness as well as the holistic needs and requirements of people with SCI to maximize their health and ability to engage in activities of daily living and social participation during extreme isolation. Such isolation has demonstrated detrimental effects on health outcomes¹⁷ and psychological wellbeing.¹⁴ Despite their concerns about vulnerability to infection, participants expressed desires to have continued and meaningful engagement in rehabilitation from a distance (e.g. online physiotherapy consultations). Such engagement in rehabilitation, even in situations of isolation such as MRSA infection in hospital, has a demonstrable positive impact in reducing pain unpleasantness and increasing perceived manageability of SCI.¹⁸ This emphasizes the need to ensure continued access to rehabilitation support, whether in person or virtually, to maintain positive outcomes and prevent deterioration in health.

It is recommended that health professionals endeavor to capture and address the health concerns identified in the present study in order to minimize health anxiety, as well as to address concerns regarding difficulties accessing rehabilitation support. The use of online/telehealth support/interventions, which can reach people across wider geographical locations, would be useful to ensure that people with SCI are still able to engage in at least some rehabilitation. This would have the benefit of enhancing and maintaining a sense of connection and community amongst others with SCI and health professionals with expertise in SCI. Indeed, such connection and quality in therapeutic relationships is often central to the shaping of rehabilitation experiences¹⁹ and should be considered in SCI care, particularly during especially isolating circumstances. In addition to the sense of connection with others, online or telehealth interventions/support may be

particularly useful to support mental and physical health for people with SCI, and previous work has demonstrated benefits of an internet-delivered mindfulness course to symptoms of depression, anxiety, and chronic pain,²⁰ and drawing parallels would likely be useful in the current context.

Rather than developing longer, more intensive online/telehealth interventions, prioritizing rapid development and implementation of accessible support structures is important. In particular, this requires a focus on ensuring equity in access to required medical supplies and personal protective equipment to facilitate safe and effective self-care is central to ensuring optimum health. Likewise, additional brief online/telehealth support for virtual rehabilitation and management of mental health concerns will be key to maximizing sense of community and minimizing risk of physical deterioration (e.g. muscle atrophy).

Limitations and future research

The findings of this study represent the opinions, attitudes and experiences of the relatively small sample studied, which may reduce ability to draw causal links between concerns. Similarly, there is potential that people who had experienced more significant distress, concerns, or barriers to healthcare may have been more likely to respond to the survey so as to make their voices heard. This may have been reflected in the gender distribution in the sample, with a large proportion of respondents being female. Growing evidence suggests that communication styles differ between sexes when discussing health, with females reportedly more likely to discuss and disclose information about their health.²¹ which may be reflected in this study's findings.

Whilst use of an online qualitative survey limited the ability to prompt participants for further detail and depth, this methodological approach helped to facilitate participation during a time when dedicating 1–2 h to an interview/focus group may have been more difficult, especially given the time involved and the urgent need to bring these experiences to the rehabilitation community. However, this approach does require literacy skills, internet access, and potentially aids to support typing of responses and could risk excluding people who are most vulnerable and without these resources, given the widely recognized 'digital divide'. Nevertheless, this approach was successful in recruitment to ensure that findings were more representative of a range of people living with SCI (and is recommended for future research with people with SCI).

Whilst the present study highlights some general concerns held by people with SCI, further work is required

to identify those who are at greater risk of both contracting the virus and experiencing deteriorations in physical and mental health as a result of social isolation and lack of access to health services. This is a particular concern given that the sample was largely White British. This means that the experiences of those from minority ethnic backgrounds have not been represented in this study, and their unique concerns surrounding increased risk of exposure and vulnerability have not been captured. Evidence suggests that people from minority ethnic groups have an increased risk of infection and death as a result of COVID-19 due to a multitude of factors such as deprivation and working in higher risk jobs,²² making this an important group to explore further. Additionally, monitoring and assessment of risk factors in those with SCI who are diagnosed with COVID-19 (regardless of ethnicity) will be essential to minimize physical and mental health deterioration. Indeed, this would be beneficial in ensuring that they are appropriately recognized as eligible for shielding and are not disproportionately and unfairly affected by the virus, receiving timely and effective care and support as appropriate.

Acknowledgements

The authors would like to express their thanks to all of the participants for their involvement in this project.

Statement of ethics

We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research.

Disclaimer statements

Contributors All authors were responsible for study design, oversight of data collection, extracting and analyzing data, interpreting results, and writing the manuscript.

Funding None.

Conflicts of interest Authors have no conflict of interests to declare.

ORCID

Jasmine Heath Hearn  <http://orcid.org/0000-0001-5988-5278>

Edward J. Rohn  <http://orcid.org/0000-0002-6092-2301>

Kimberley R. Monden  <http://orcid.org/0000-0002-5207-0452>

References

- 1 American Psychological Association. How COVID-19 impacts people with disabilities. May 6, 2020. [cited 2021 January 29]. Available from <http://www.apa.org/topics/covid-19/research-disabilities>.
- 2 Berlowitz DJ, Wadsworth B, Ross J. Respiratory problems and management in people with spinal cord injury. *Breathe* 2016;12(4):328–40. doi:10.1183/20734735.012616.
- 3 van den Berg MEL, Castellote JM, de Pedro-Cuesta J, Mahillo-Fernandez I. Survival after spinal cord injury: a systematic review. *J Neurotrauma* 2010;27:1517–28.
- 4 Winslow C, Bode RK, Felton D, Chen D, Meyer PR. Impact of respiratory complications on length of stay and hospital costs in acute cervical spine injury. *Chest* 2002;121:1548–54.
- 5 Korupolu R, Stampas A, Gibbons C, Hernandez Jimenez I, Skelton F, Verduzco-Gutierrez M. COVID-19: screening and triage challenges in people with disability due to spinal cord injury. *Spinal Cord Ser Cases* 2020;6:35.
- 6 World Health Organization (WHO). Disability considerations during the COVID-19 outbreak. 2020. [cited 2021 April 30] Available from <https://apps.who.int/iris/bitstream/handle/10665/332015/WHO-2019-nCov-Disability-2020.1-eng.pdf>.
- 7 Stillman MD, Capron M, Alexander M, Di Giusto ML, Scivoletto G. COVID-19 and spinal cord injury and disease: results of an international survey. *Spinal Cord Ser Cases* 2020;6:21. doi:10.1038/s41394-020-0275-8.
- 8 Monden KR, Andrews E, Pilarski C, Hearn J, Wudlick R, Morse L. COVID-19 and the spinal cord injury community: concerns about medical rationing and social isolation. *Rehabil Psychol* 2021. [Accepted, in press].
- 9 Braun V, Clarke V, Boulton E, Davey L, McEvoy C. The online survey as a qualitative research tool. *Int J Soc Res* 2020. E-pub ahead of print 16 August 2020. doi:10.1080/13645579.2020.1805550.
- 10 Grogan S, Turley E, Cole J. ‘So many women suffer in silence’: a thematic analysis of women’s written accounts of coping with endometriosis. *Psychol Health* 2018;33(11):1364–78.
- 11 Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;3(2):77–101.
- 12 Braun V, Clarke V. Reflecting on reflexive thematic analysis. *Qual Res Sport Exerc Health* 2019;11(4):589–97.
- 13 Burr V. Social constructionism. In: Wright J, (ed.) *International encyclopedia of the social & behavioral sciences*. 2nd ed. Elsevier; 2015. p. 222–7. doi:10.1016/B978-0-08-097086-8.24049-X.
- 14 Abad C, Fearday A, Safdar N. Adverse effects of isolation in hospitalised patients: a systematic review. *J Hosp Infect* 2010;76:97–102.
- 15 Catalano G, Houston SH, Catalano MC, Butera AS, Jennings SM, Hakala SM, *et al*. Anxiety and depression in hospitalized patients in resistant organism isolation. *South Med J* 2003;96:141–5.
- 16 Sharma A, Pillai DR, Lu M, Doolan C, Leal J, Kim J, *et al*. Impact of isolation precautions on quality of life: a meta-analysis. *J Hosp Infect* 2020;105:35–42.
- 17 Tran K, Bell C, Stall N, Tomlinson G, McGeer A, Morris A, *et al*. The effect of hospital isolation precautions on patient outcomes and cost of care: a multi-site, retrospective, propensity score-matched cohort study. *J Gen Intern Med* 2017;32:262–8. doi:10.1007/s11606-016-3862-44.
- 18 Gillett JL, Duff J, Eaton R, Finlay K. Psychological outcomes of MRSA isolation in spinal cord injury rehabilitation. *Spinal Cord Ser Cases* 2020;6:63.
- 19 Gelso C. A tripartite model of the therapeutic relationship: theory, research, and practice. *Psychother Res* 2014;24:117–31.
- 20 Hearn JH, Finlay KA. Internet-delivered mindfulness for people with depression and chronic pain following spinal cord injury: a randomized, controlled feasibility trial. *Spinal Cord* 2018;56(8):750–61. doi:10.1038/s41393-018-0090-2.
- 21 Robinson ME, Riley JL, Myers CD, Paps RK, Wise EA, Waxenberg LB, *et al*. Gender role expectations of pain: relationship to sex differences in pain. *J Pain* 2001;2(5):251–7. doi:10.1054/jpai.2001.24551.
- 22 Public Health England. Disparities in the risk and outcomes of COVID-19. 2020. [cited 2021 April 30]. Available from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/908434/Disparities_in_the_risk_and_outcomes_of_COVID_August_2020_update.pdf.